



HEREDITARY
NEUROPATHY
FOUNDATION

SUMMER 2020

Letter from the CEO	1
Featured Article	2
TRIAD	4
GRIN	6
HNF News	7
Team CMT	8
Partnership Highlight	10
Community	12
CMT-Connect	14
Center of Excellence	18
Events	BC

cmtupdate

CMT IS RUFF

September
Awareness Month

Pg. 2

Matt Downing
HNF's New Board Chairman
Pg. 7

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Kerin Reilly

HNF STAFF

Allison Moore
Founder, CEO
allison@hnf-cure.org

Courtney Hollett
Executive Director
courtney@hnf-cure.org

Joy Aldrich
Advocacy Director
joyaldrich@hnf-cure.org

Cherie Gouaux
Accounting Manager
cherie@hnf-cure.org

Estela Lugo
Program Development Manager
estela@hnf-cure.org

Bernadette Scarduzio
Social Media Coordinator
bernadette@hnf-cure.org

DESIGN

BolleDesign.com

The Hereditary Neuropathy Foundation's mission is to increase awareness and accurate diagnosis of Charcot-Marie-Tooth (CMT) and related Inherited Neuropathies, support patients and families with critical information to improve quality of life, and fund research that will lead to treatments and cures.

www.hnf-cure.org

CMT UPDATE SUMMER 2020



Allison T. Moore

Founder and CEO

Hereditary Neuropathy Foundation

Dear Friends,

We hope you all have been able to make the best of this very unique summer. As we wrap up the third quarter of 2020, we are hanging strong despite the world of turmoil from COVID-19.

I'm so proud of our board of directors, our scientific advisors and researchers, HNF executive team and staff, for rallying and adapting to new ways of conducting business. In this issue, you'll receive updates on our research initiatives, including our gene therapy program for rare types of CMT. You'll also learn how HNF is speeding up clinical trial readiness with groundbreaking natural history studies, and get an update on how HNF is supporting Dr. David Herrmann's research to accelerate clinical trials for CMT, which will enhance our knowledge on the progression of CMT over time and improve clinical trial protocols to measure potential positive outcomes.

Despite in-person events being put on hold, our team has been busy keeping our community connected and informed with resources and tools to manage their CMT via Zoom-a-thons, CMT-Connect Webinars, and our first-ever self-improvement Master Class, "Bold Vision" with world renowned speaker, Lisa McCarthy on Sept. 16th. This September Awareness Month may be the most important one yet with many of us working from home and taking action remotely. The potential to make a huge impact in raising CMT awareness, funds for research and valuable patient programs is literally at our very fingertips.

This year, we've put together 10 Fun & Furry ways to be a true CMT advocate and play a role in progress for millions of patients worldwide.

I am so grateful to have you by our side. Let's do this! Let's cure CMT!

All the best,



PS: HNF relies on the generosity of our community to help support our programs and research. With most of our fundraisers put on hold for the moment any donation is greatly appreciated. [**CLICK HERE TO DONATE TODAY!**](#)



SEPTEMBER IS CMT AWARENESS MONTH 2020 THEME “CMT IS RUFF”

Although we're not ready to say goodbye to summer, September is fast approaching and the Hereditary Neuropathy Foundation (HNF) is once again ready to take on Charcot-Marie-Tooth (CMT) Disease. We are continuing our mission to increase awareness, raise research funds and find a cure for CMT!

As patients, we know firsthand the challenges that come with living with CMT. We also know that it can be hard for others to understand what daily life is really like with a neurological disease... but there are those special kinds of friends who bring unconditional love as well as physical and emotional support for so many CMT patients... our pups!

Inspired by our favorite CMT Service Dog, Marvin, HNF would like to invite all dog owners (and non dog-owners) and their furry besties to take a bite out of CMT this September. Here are 10 fun ways and events!



1. “CMT is Ruff” Bandana

Purchase a Bandana for your pup or yourself! Raise awareness and support research while sporting our exclusive bandana. Wear it any way and any where or style up your pup and post your photos on social media with #cmtisruff & #cmtwegotthis to share our important mission with friends and family! Photo with the most likes wins a \$50 giftcard to chewy.com. (Must be wearing bandana)

CLICK TO PURCHASE:
weblink.donorperfect.com/CMTISRUFF

2. Facebook Frames

Show your support for CMT families and awareness across the globe by upgrading your Facebook profile photo with your choice of 2 exclusive frames!

VISIT: hnf-cure.org/september_awareness_2020/



3. September Awareness Kit

HNF has designed a September Awareness Month kit to assist you with spreading the word about CMT with every \$30 donation.

Each Kit includes:

- * Pair of comfy CMT socks that say, "If you can read this, please help me up"
- * Neurotoxic drug wallet card
- * Diagnosis Chart
- * Bumper sticker
- * AFO guide
- * GRIN Flyer

VISIT: hnf-cure.org/september-cmt-awareness-month-kit/

4. Virtual Dog Walk - Join us Sept 25-26!

- * Step #1: Purchase Your "CMT is Ruff" Bandana weblink.donorperfect.com/CMTISRUFF
- * Step #2: Share our Event page on social media and ask friends/family to support CMT research hnf-cure.org/cmt-virtual-dog-walk/
- * Step #3: Walk/roll with your pup any time on **Saturday 9/25** and **Sunday 9/26** wearing their bandana and post your photos/videos on social media with #cmtisruff & #cmtwegotthis

5. Flat Marvin

Don't have a pup? No Problem! Marvin, the CMT Service Dog, to the rescue! Just download and print. Cut him out and stage your own photoshoot to spread CMT awareness. Tag us on social media using #cmtisruff & #cmtwegotthis.

Want to learn more about service dogs for CMT patients? Watch our exclusive

interview with the real Marvin and his owner, Diana [here!](#)

DOWNLOAD HERE: www.hnf-cure.org/wp-content/uploads/2020/07/Marvin-Flyer.pdf

6. Neurotoxic Drug Wallet Card

HNF created a neurotoxic drug wallet card to alert CMT patients about medications that may worsen their neuropathy. You can provide this vital information easily to all your healthcare providers when they prescribe a medication.

With a minimum donation of \$10, you'll receive a neurotoxic drug wallet card. Just fill out the form below and HNF will send your card via snail mail to arrive within seven days.

VISIT: weblink.donorperfect.com/neurotoxicmeds

7. Help Support HNF with the RoundUp app!

HNF has partnered with an app called RoundUp that allows you to round up and donate the change from your credit or debit card purchases to support us – all automatically and without hassle. You can even cap the maximum amount you want to donate in a given month.

VISIT: hnf-cure.org/roundup-app/

8. CMT Dance Party

Celebrate CMT Awareness Month with your best dance videos on Instagram or Facebook! Post your or your pup's best moves with #cmtwegotthis & #cmtisruff. We'll share our favorites on our social media and email blasts!

9. Follow us on Social Media

Connect with our growing CMT online community and be the first to learn about new resources, events and products when you follow us on social media! Submit your own photos and posts by tagging us using hashtag #cmtwegotthis

Don't forget to print your Selfie Card and post pictures, making sure you tag a friend.

VISIT: hnf-cure.org/social-media-outlets/

10. Bold Vision Master Class

Join us for our first groundbreaking 90 minute Bold Vision Master Class with international coach, speaker and cofounder of The Fast Forward Group, Lisa McCarthy.

This interactive and engaging virtual class will be specially tailored for individuals living with CMT who want to explore new possibilities for their lives. Lisa is an in-demand public speaker. Known for her relatability, authenticity and candor – clients SUCH AS Facebook, Google, JP Morgan Chase, NBCU, Disney, Visa, Nike, Aon and YPO count on her to leave people inspired and in action.

TO REGISTER: weblink.donorperfect.com/BoldVision

VISIT HNF's September Awareness HUB on the HNF site to get involved! hnf-cure.org/september_awareness_2020/



Accelerate Clinical Trials in Charcot-Marie-Tooth Disease (ACT-CMT)

Calling CMT1A Patients Ages 18-75



Dr. David Herrmann

This study is a new international research project funded by the National Institutes of Health (NIH) called *Accelerate Clinical Trials in Charcot-Marie-Tooth Disease (ACT-CMT)*. Dr. David Herrmann at the University of Rochester is the study's Principal Investigator. There are 3 participating centers in the USA.

- * University of Rochester, NY
(Dr. David Herrmann)
- * University of Pennsylvania, PA
(Dr. Steve Scherer)
recruitment completed
- * University of Iowa, IA
(Dr. Mike Shy)

This study is enrolling people with CMT1A who are aged 18-75.

The purpose of this study is to determine the best way to measure the progression of Charcot-Marie-Tooth Disease Type 1A (CMT1A) over time. This study is important to help us to prepare for clinical trials. We are looking at new ways of measuring changes in CMT1A progression over a short period of time and assessing their usefulness in measuring effects of treatments in future clinical trials.

In addition to measurements that are currently used to measure progression of CMT1A such as strength and sensation, this study would also include the following:

- * Two questionnaires (the CMT Health Index and Overall Neuropathy Limitation Scale) that explore how you think CMT1A affects you
- * CMT Functional Outcome Measure (CMT-FOM) which assesses balance, walking, standing up from sitting in a chair, and manual dexterity
- * We will also test your ability to feel nylon monofilaments (like fishing line) and photographing a small area of your hand using a non-invasive microscope that can look into the skin and see nerve endings

- * Nerve conduction studies on one arm and one leg
- * For some participants, an MRI scan of your lower leg muscles

The study visits are approximately 4 hours (with an additional hour for optional MRI). The study visits are at 6-12 month intervals for up to 3 years. Participants will receive an honorarium and reimbursement of qualified travel expenses.

For more information about participating, please contact:

University of Rochester
Steffen Behrens-Spraggins
(585) 275-5760
Steffen_Behrens-spraggins@URMC.
Rochester.edu

University of Iowa
Alexa Bacha
(319) 467-5006
alexa-bacha@uiowa.edu



Movement is Medicine™

Summit Postponed

Due to Covid-19 and travel demands, HNF has postponed the Movement is Medicine™ Summit to November 5-6, 2021.

Although we are saddened and disappointed to be missing this special weekend and all of its meaningful connections, the safety and health of our community will always be our top priority. We've been working tirelessly to produce content and virtual programs to help the CMT Community during this time of uncertainty. As a patient advocacy group, we thrive on providing you with tools to help you navigate through life.

Virtual Tools:

www.hnf-cure.org/living-with-cmt/virtual_tools

Wishing you all a safe and wonderful summer!

Keep moving and tag us on social! #CMTwegotthis

Donate Today:

www.hnf-cure.org/donation-form

Do you have CMT4A (GDAP1)?

Investigators are looking for patients with a **CMT4A (GDAP1) diagnosis**.
If you would like to participate, please email Estela@hnf-cure.org and we'll coordinate an introduction for you.

For medical professional:
if you have patients with
CMT4A (GDAP1) click the
poster to go to the survey.



Walk with us towards the first GENE THERAPY treatment for CMT4a

PHOTO: GDAP1 PATIENT, ESTELA LUGO

CHARCOT-MARIE-TOOTH

IF YOU HAVE PATIENTS WITH

GDAP1 (CMT4A)

Click Below

OUR GENE THERAPY STUDY NEEDS YOU!

WWW.SURVEYMONKEY.COM/R/GDAP1

 HEREDITARY NEUROPATHY FOUNDATION





Matt Downing Takes the Reins as HNF's New Board Chairman

The Hereditary Neuropathy Foundation (HNF) is happy to announce on July 1, 2020, that Matt Downing has been selected as Chairman of the HNF Board of Directors. Matt, a CMT patient and a father of three children with CMT, has been serving as an HNF board member for over 10 years and most recently held the role of Board Secretary. We are thrilled to have Matt take this leadership role and excited to see what the future holds for HNF!

Matt is currently the Chief Marketing and Innovations Officer at MedPower, a cloud-based online learning company focused on serving the healthcare industry. In his role as CMO, Matt leads MedPower's global marketing and product teams, guiding the company's marketing strategy, product development, communications, branding and analytics.

Prior to MedPower, Matt served as Chief Marketing Officer at TriPlay, a personal cloud services and audio entertainment start-up in New York City. Prior to TriPlay, Matt ran sales and marketing for SiriusXM's Streaming Services and Direct to Consumer divisions. During his tenure, Matt helped SiriusXM grow from a small satellite radio start-up to the world's largest radio broadcaster with over 27 million subscribers. Prior to SiriusXM, Matt served as VP, Marketing at DIRECTV and ran a variety of national accounts for both Grey Advertising and Young & Rubicam. Matt is a graduate of the University of Michigan, where he studied marketing and business management.

Special thanks to Joy Kaye for her years of service to HNF. We are happy to report that Joy will continue to participate as an HNF board member.

TEAM CMT

"We succeed in enterprises which demand the positive qualities we possess, but excel in those which also make use of our defects."

– Alexis de Tocqueville

Senior Olympian,
Christine Wodke



Team CMT 10 Years Strong

Team CMT was formed in 2010 and we ran our first race in Brown Deer, Wisconsin at the end of April 2010. We had three founding members, Chris Wodke, Founder Team CMT, and her supportive friends Cheryl and Robert Kearney. The team has grown quite a bit since then.

Team CMT in 2020

Members: 233 in 41 states

Countries: 16 - USA, Australia, Canada, England, Finland, Vietnam, Iran, Scotland, France, Turkey, Poland, Norway, Mexico, Wales, Ireland, Sweden.

Sports represented: Running, walking, martial arts, cycling, swimming, kayaking, weight lifting, Nordic skiing, biathlon, alpine skiing, track, triathlon.

Team Member Accomplishments include:

- * Half and full marathon finishes around the US and in member countries, including the Boston Marathon and TCS New York Marathon
- * Circumnavigating Big Island of Hawaii by kayak
- * Multiple Ironman Triathlons
- * Represented Team USA members including appearance at World Championships
- * Multiple team members appearing at Para-triathlon National Championships
- * Gran Frodo finishers
- * Leadville 100 mile bike race
- * Multiple year appearance at the TD Bank Five Boro Bike Ride in New York
- * UPenn Orphan Disease Center Million Dollar Bike Ride

Founding Story

Chris Wodke founded the group because when she was diagnosed she could not believe she had never heard of CMT — the most common inherited neuropathy.

“It did not seem right to me that most people had no idea what it was”.

Chris was determined to change that. She knew there would be no cure without wider recognition of CMT.

Chris also witnessed that many in the community lived without hope. Most of them had been told not to exercise when they were diagnosed. At one time the thinking was that exercise would accelerate the disease. That has been found not to be true, but the belief was still common in the community.

It was a common belief by many even in the medical community, that someone with CMT could not run. That is true even for many of our Team CMT athletes who proudly wear their Team CMT uniforms while participating in sports or workouts their bodies allow.

Those of us that can still run have done runs, and multi-sport events in the U.S and in many parts of the world. Team members have put names and faces to this disease at a time when having CMT still carries a stigma. Many family members, including some my own, refuse to discuss CMT.

I am so proud of the work our members have done to change perceptions about CMT. Now I see discussions in the community about the type of exercise that can be done. Our partner, the Hereditary Neuropathy Foundation, has been a leader in promoting exercise for those with CMT. They have hosted multiple "Movement is Medicine™" summits, which is why we chose to partner with them shortly after the team was formed.

I am so grateful for the work our team members continue to put in. I know that CMT poses challenges for us to stay active. By being active we prove many in the medical community wrong and inspire our CMT community as positive role models.

Many of our family members have joined in support of an afflicted friend or family member. We are so grateful for their support - it means more than I can possibly express.

These 10 years have gone by quickly. When we started with three members, I never dreamed we would grow this large. I never imagined all the team members I'd meet from around the country who have humbled and inspired me.

Often when I race, I am approached by someone with a family member with CMT. It is not unusual for someone with CMT to have never met a fellow individual with CMT outside of their family. I am always happy to welcome them into our growing community.

Although we are currently challenged by the virus concerns, someday soon we will be back to our mission. A few cancelled races is nothing compared to training and racing with CMT.

WE'VE GOT THIS.

Cheers to many more wonderful years and members for our **TEAM CMT!**

Join Team CMT [https: www.hnf-cure.org/team-cmt](https://www.hnf-cure.org/team-cmt)

Press Release: Pharnext provides regulatory and clinical update on PXT3003 Phase III study for the treatment of Charcot-Marie-Tooth Type 1A.

US Food and Drug Administration has agreed with Pharnext and provided clear guidance on the regulatory pathway to approval for PXT3003, including key design elements of a single pivotal Phase III study

PARIS, France, 7:00 a.m., June 10, 2020 (CET) – Pharnext SA (FR0011191287 – ALPHA), a biopharmaceutical company pioneering new approaches to developing innovative drug combinations based on big genomics data and artificial intelligence, today provided an update on the regulatory and clinical status of PXT3003, its lead program in Charcot-Marie-Tooth Type 1A (“CMT1A”).

Regulatory Update

PXT3003 is a novel drug candidate for the treatment of CMT1A and has been granted both Orphan Drug Designation and Fast Track Designation by the US Food and Drug Administration (“FDA”). In Pharnext’s previous interactions with FDA, the agency provided guidance that an additional Phase III study would be required. Based on our most recent interactions with FDA through a Type C meeting, FDA has now provided a very clear path to NDA submission for approval of our lead clinical program.

The FDA has agreed with the key elements of Pharnext’s approach for the developmental pathway to approval for PXT3003. Specifically, the FDA has indicated that a single pivotal Phase III study in CMT1A delivering robust results could be sufficient for approval of PXT3003. This study design will be similar to the earlier Phase III study of PXT3003 that yielded encouraging top line results in October 2018. The FDA has agreed that the primary endpoint will again be Overall Neuropathy Limitations Scale (ONLS). Notably, the FDA has also agreed that the factorial study requirement for combination drugs can be carried out in a preclinical CMT1A disease animal model, and not in a human Phase III clinical trial as typically required. The animal factorial study, a requirement for NDA filing, will be done under GLP or GLP-like conditions and will have a similar study design and use the same CMT1A model as our previously successful preclinical factorial study.

Phase III Trial Design Update

For the upcoming Phase III pivotal study, as recommended by FDA, Pharnext will use ONLS as the primary endpoint, as was used in the previous Phase III study. We will have two arms in the study which will compare the high dose vs placebo. The high dose showed encouraging results in the earlier Phase III study. In addition, we have resolved the past manufacturing issue with our high dose oral solution and will now use the earlier successful low dose oral solution formulation in a higher volume to deliver the high dose in our upcoming Phase III trial. We will also be utilizing a more convenient new unit dose package format, stick packs (liquid sachets), that will assure optimal patient compliance and more accurate dosing.

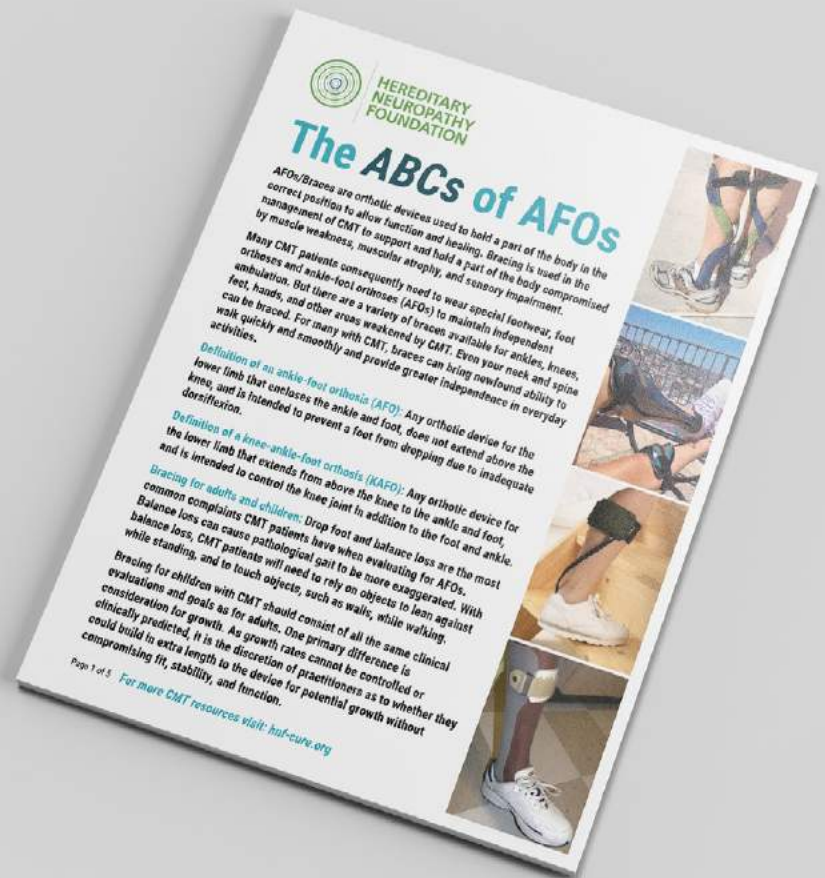
Pharnext plans to initiate the final pivotal Phase III clinical study before the end of Q1 2021.

Dr David Horn Solomon, Chief Executive Officer commented, “We are grateful that the FDA has provided strong and specific guidance to complete pivotal studies towards NDA submission and approval for PXT3003 in CMT1A. Both the Phase III clinical trial as well as the preclinical animal study will be informed in their design by the earlier Phase III clinical trial that provided encouraging top-line results, and the earlier animal study that was successful, respectively. We have addressed earlier manufacturing issues and look forward to PHARNEXT | CREATING NEW SOLUTIONS Page 2 initiating the Phase III clinical trial before the end Q1 2021. Our goal at Pharnext is to provide CMT1A patients and their caregivers a new therapeutic to treat this disease where no therapy currently exists.”



HNF Collaborates with Italian CMT Organization ACMT-Rete on the ABCs of AFOs

Now Available in English & Italian!



Researching and shopping for AFOs can be incredibly overwhelming, especially for first-timers. What kind of braces should you get? What kinds are available? What are the differences, similarities, pros and cons? Most CMT patients have no idea where to even begin...

Don't you wish there was an AFO guide and checklist you could bring to your orthotist to ensure you're getting the best care and leg brace options possible? The Hereditary Neuropathy Foundation thought so too!

Last Fall, HNF teamed up with Mitchell Warner, CPO, Ortho Rehab Designs Prosthetics and Orthotics, INC., and a panel of CMT patients to thoughtfully put together a comprehensive 10-page packet to educate and empower our community. Originally launched for our [Movement Is Medicine™ Summit](#) AFO workshop, the exclusive PDF has now been made available as a download on our website.

Most recently, HNF had the honor of collaborating with Fillipo Genovese and his team at [ACMT-Rete](#), an Italian non-profit organization for CMT, to translate the entire guide and checklist from English to Italian for their community. We're very excited to work internationally with other advocacy groups and provide much needed resources to CMT families worldwide!

English Guide:

www.hnf-cure.org/free-download-form

Italian Guide:

<https://bit.ly/32PODDO>

Please reach out to Estela@hnf-cure.org if you would like to translate the ABCs of AFOs guide in your language.



Ann Taylor Jones – Covid Nurse Working on the Front Lines

Ann Taylor Jones, a CMT1A patient, was told her whole life that she could never be a nurse. Now she works as a full-time ICU nurse treating COVID-19 patients.

Ann grew up with CMT in her family. Her father inherited it from his mother and one of her two siblings also has it, so it was no surprise when she began noticing symptoms around the age of eight. "Sports and recreational activities became harder for me, but it wasn't until my college years when the nerve pain started." She could feel her muscles atrophying and would soon have no choice but to opt for five extensive surgeries including: bilateral foot reconstructions, tendon transfers, achilles lengthening, hammer toe corrections and fusions. "I was using leg braces at one point but now after the surgeries, I'm glad to say I don't need them anymore."

The surgeries have improved her quality of life dramatically with the most recent surgery taking place this past January. "On a scale of 1 to 10, my daily pain has gone from a 7 or 8 to about a 3 or 4."

Not all of Ann's journey has included physical pain. She recalls an emotionally painful event during her junior year of college when she had been experiencing ulcers and blood flow issues following a surgery, which resulted in extended time in a cast. One of her instructors told her that she would not be allowed to partake in the clinical sessions while wearing a boot. Thankfully, Ann recognized this as a violation of the ADA (Americans with Disability Act) and worked with student affairs to reverse the decision and partake in the clinic.

When it was time to interview for a job, Ann chose not to disclose her CMT. "I didn't want to be judged for having a disability— there's not much info on it and I was afraid people would not understand. There are still a fair amount of coworkers who don't know." The colleagues who are aware are very supportive. If there's an instance where something needs to be grabbed in a hurry, they will rush on her behalf. She sometimes struggles with opening things but says for the most part everything has a "flip open" top.

"I'm lucky to work in the ICU because I only have one or two patients at a time. There isn't much running back and forth. I am on my feet a lot, which can be challenging, but there are moments in between when I can sit and put my feet up for a



while. Not everyday is physically exhausting, some days I'm handling mostly administrative tasks. Recently, my work days have gone from three to five days at twelve-hour shifts each. I find myself asking my husband to meet me in the driveway after my 45-minute drive home to help me into the house and into a pair of compression socks to relieve the swelling."

Ann is aware that she won't always be able to sustain the pace she is working now and is currently in school to become a nurse practitioner. Her advice to those living with CMT and passionate about nursing is to "go for it."

"There are so many areas of nursing to go into. Not all are as physically demanding as ICU. I'm a better nurse because of my CMT. My empathy and ability to relate to what my patients are going through is valuable and comforting to them. When someone is in pain, I can compassionately tell them, I know... I've been there too."

Watch our full CMT-Connect IG interview here:
<https://bit.ly/3hAeDpN>



Find Others Near You!

Here's how you do it:

Step 1:

Join the HNF CMT Inspire community.
(www.inspire.com/groups/charcot-marie-tooth-cmt)

Step 2:

When you're in the HNF CMT community (HNF logo in the banner), on the far right, **click on** "Find Members."

Step 3:

On the left side of the page, you can **enter and search by zip code, state, country, age or gender.**

Step 4:

Send them a message to introduce yourself and make a plan to meet in person.



Are you active on Ebay?

The Hereditary Neuropathy Foundation can earn research dollars when you choose us as your charity.

Selling for charity is simple!

Step 1:

After you complete your item to sell there is an option "Donate a percentage of your sale to the charity of your choice and we'll give you a credit on basic selling fees for sold items." Click on the search field and **select the Hereditary Neuropathy Foundation as your charity.**

Step 2:

Sell & Ship

Sell and ship to your customer as usual. No additional steps or paperwork required.

Step 3:

Receive a Donation Receipt

Within a few weeks, and after the buyer has paid, PayPal Giving Fund will automatically send the donation to the Hereditary Neuropathy Foundation and send you a donation receipt. eBay will also credit you an equal percentage of your fees.

Dear Lainie,

How do I stop my orthotics from making a squeaking sound when I walk? It's really embarrassing! Please help!

From,
Laurie in Minneapolis

Hi Laurie

I get it! As an AFO wearer with funky CMT feet, the last thing I want to do is draw additional attention to them with embarrassing squeaking sounds. I'm pretty sure an annoying squeaking sound would make almost anyone self-conscious, but especially those of us with feet problems.

So, the squeaking sound you're referring to is typically caused by friction when the orthotic rubs against the inside of a shoe. There are several easy hacks to stop an orthotic from squeaking.

One quick fix is to apply a thin layer of Vaseline under the insole so that the shoe and orthotic rub together more smoothly. Another hack for this is to put a dryer sheet (I'm a lavender scent girl) inside your shoe and underneath your orthotics. This will serve to create a barrier and put an end to the squeaking sound. Plus, it helps stop orthotics from smelling if that is a problem you've encountered.

I hope the hacks above help & be sure to check out Trend-Able for other orthotic/AFO hacks & more!



Xoxo
Lainie

Lainie Ishbia, MSW
Disability Speaker & Blogger
Trend-ABLE



Meditation for CMT is a No-Brainer

WRITTEN BY: ESTELA LUGO

When we think about effective treatments for CMT symptoms, how many of us actually think of meditation? Sure, we may have heard some buzz on social media regarding its benefits or a few raving testimonies from our “Yogi friends,” but can it really provide relief for CMT patients?

The overwhelming research and evidence points to a resounding YES... Here are 7 reasons why!

1. It Calms the Nerves

CMT is a disorder of the nervous system, also known as the control center of the body. As one of the most vital systems in the human body, it’s responsible for both our voluntary and involuntary motions such as breathing, digesting and sweating.

Meditation has been proven to soothe the nerves and dramatically reduce the many negative effects brought about by the **sympathetic nervous system** such as anxiety, tension, fatigue and depression.

Not only does meditation reduce the negative effects of our nervous system, it actually boosts and activates the “good” nervous system by slowing down our heart rate, breathing rate, blood pressure and sweating, and by activating the **parasympathetic nervous system**.

2. Better Breathing

Over the past few years, it's become increasingly recognized that Phrenic and Diaphragmatic weakness in CMT disease may be more common than generally acknowledged, causing symptoms of breathlessness and orthopnea, as well as the development of hypercarbia.

Some research has even shown that in addition to enhancing breathing via oxygen uptake, nutrient flow, and circulation, meditation also enhances and promotes diaphragmatic breathing. The **diaphragm** is the primary muscle of respiration and a lobe found below the rib cage. When we inhale, it contracts and flattens creating a vacuum effect that pulls air into the lungs. Another key player in respiratory function shown to benefit from meditation is the **phrenic nerve**, as it provides exclusive and crucial motor control of the diaphragm.

3. Brain Power

Meditation also has an amazing variety of neurological benefits by improving connectivity between brain regions. A recent study showed participants who'd been meditating for an average of twenty years had more grey matter volume throughout the brain. Just eight weeks of [Mindfulness-Based Stress Reduction \(MBSR\)](#) was found to increase cortical thickness in the hippocampus, which governs learning and memory, and in certain areas of the brain that play roles in emotion regulation and self-referential processing. One of the most interesting studies in the last few years, carried out at Yale University, found that mindfulness meditation decreases activity in the default mode network (DMN), the brain network responsible for mind-wandering – a.k.a., "monkey mind."

4. Soothes Pain

One of the most significant and disruptive symptoms of CMT is pain. The latest medical advances show that meditation and mindfulness can be even more powerful than many commonly prescribed painkillers.

Based on an ancient form of meditation known as "[mindfulness](#)," [mindfulness meditation](#) has been shown in clinical trials to reduce chronic pain by 57 percent. Experienced meditators can reduce it by over 90 percent.

Imaging studies show that mindfulness can soothe the brain patterns underlying pain and over time, can alter the structure of the brain itself. Patients report no longer feeling pain with the same level of intensity.



Many hospitals and pain clinics are prescribing mindfulness meditation to help patients cope with an arising range of diseases such as cancer (and the side effects of chemotherapy), heart disease, diabetes, and arthritis. It is also used for back problems, migraine, fibromyalgia, chronic fatigue, irritable bowel syndrome, and even multiple sclerosis.

As explained in the book, [You Are Not Your Pain: Using Mindfulness to Relieve Pain, Reduce Stress, and Restore Well-Being – An Eight-Week Program](#), meditation achieves remarkable results because it turns down the "volume" control on pain.

5. Sweet Dreams

Quality sleep plays a vital role in fighting fatigue while remaining functional and active with CMT. One powerful neurochemical, "**melatonin**" is critical to the falling asleep process. Stress is melatonin's number one enemy, inhibiting the natural sleep cycle. Low melatonin levels initiated by the stress create all types of mental, emotional, and physical problems. Produced in the brain, melatonin is a hormone that peaks just before bedtime, ensuring a night of deep, restful sleep.

In a Rutgers University sleep study, melatonin levels for meditation practitioners were boosted by an average of 98% with many participants having increases by more than 300%!

(Continued next page)

Meditation effectively re-balances all of the biological markers for night ensuring restful sleep and rejuvenated mornings.

6. Focus & Concentration

In the modern age of social media, schooling, Zoom meetings and every other worldly distraction in between, it's no surprise that so many children and adults struggle with focus and concentration. One of the central benefits of meditation is that it improves attention and concentration. One recent study found that just a few weeks of meditation training improved focus and memory. Meditation doesn't have to be intensive to have an effect. Scientists at the University of North Carolina at Charlotte found that students were able to improve their performance on tests of cognitive skill after just four days of meditation training for only 20 minutes per day. Mindfulness training improved both GRE reading-comprehension scores and working memory capacity while simultaneously reducing the occurrence of distracting thoughts.

7. Balances Mental/Emotional Health

Let's be honest... CMT can take a significant toll on one's emotional health. Feelings of loss, isolation and anxiety are common with any progressive disease. According to the world famous author of *Minding the Body, Mending the Mind*, Dr. Borysenko, meditation teaches us just how important it is to regularly activate the body's natural "relaxation response" – training our minds through meditation so that stress responses simply can't take over, perpetually maintaining our mental/emotional health and general well-being.

A new study from the University of Oxford finds that mindfulness-based cognitive therapy (MBCT) may be an effective way to wean people off even successful courses of antidepressants and has shown to be just as effective as antidepressants for preventing a relapse of depression. Not only does meditation change the brain, but it changes our subjective perception and feelings as well.



Where to Start?

The Mayo clinic reminds us that there is no right way or wrong way to meditate. What matters is that meditation helps reduce stress and provides a sense of feeling better overall.

Some ways to meditate can include:

- * **Guided meditation.** Sometimes called guided imagery or visualization, with this method of meditation you form mental images of places or situations you find relaxing. You try to use as many senses as possible, such as smells, sights, sounds and textures. You may be led through this process by a guide or teacher.
- * **Mantra meditation.** In this type of meditation, you silently repeat a calming word, thought or phrase to prevent distracting thoughts.
- * **Mindfulness meditation.** This type of meditation is based on being mindful, or having an increased awareness and acceptance of living in the present moment.

In mindfulness meditation, you broaden your conscious awareness. You focus on what you experience during meditation, such as the flow of your breath. You can observe your thoughts and emotions, but let them pass without judgment.

- * **Qi gong.** This practice generally combines meditation, relaxation, physical movement and breathing exercises to restore and maintain balance. Qi gong (CHEE-gung) is part of traditional Chinese medicine.
- * **Tai chi.** This is a form of gentle Chinese martial arts. In tai chi (TIE-CHEE), you perform a self-paced series of postures or movements in a slow, graceful manner while practicing deep breathing.
- * **Transcendental Meditation®.** Transcendental Meditation is a simple, natural technique. In Transcendental Meditation, you silently repeat a personally assigned mantra, such as a word, sound or phrase, in a specific way.

This form of meditation may allow your body to settle into a state of profound rest and relaxation and your mind to achieve a state of inner peace, without needing to use concentration or effort.

- * **Yoga.** You perform a series of postures and controlled breathing exercises to promote a more flexible body and a calm mind. As you move through poses that require balance and concentration, you're encouraged to focus less on your busy day and more

ASK THE EXPERT

As the popular meditation app, [Headspace](#) notes:

"Meditation isn't about becoming a different person, a new person, or even a better person. It's about training in awareness and getting a healthy sense of perspective. You're not trying to turn off your thoughts or feelings. You're learning to observe them without judgment. And eventually, you may start to better understand them as well."

***WATCH OUR NEW GUIDED MEDITATION VIDEO HERE!**

<https://www.hnf-cure.org/cmt-connect-webinars/>

PAST WEBINARS

- * Guided Meditation
- * Work From Home Job Training & Placement
- * CMT & Telemedicine
- * Align with Happiness
- * CMT & Capture Proof
- * CMT & Genetic Testing
- * CMT & Covid-19
- * Healing from the Inside Out
- * CMT Resources with Inspire
- * Dating & CMT
- * How to Exercise in the Pool with Bernadette Scarduzio
- * accessibleGO.com: A New Way to Travel with Disabilities
- * Bemer Technology
- * Panetta Physical Therapy
- * CMT & Balance
- * CMT & Your Nutrition
- * CMT&Me App
- * CMT & Finances
- * Ability360 Sports & Fitness Center
- * Active Hands
- * Cannabis & CBD for CMT
- * CMT & Canine Companions

VIEW PAST WEBINARS:

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CAUTION

Nitrous Oxide, or laughing gas, is commonly used to reduce anxiety during dental or medical procedures. It is listed as Moderate to Significant Risk on the Neurotoxic Drug List because overexposure can lead to anemia or a vitamin B-12 deficiency. The latter can cause additional nerve damage, which can lead to limbs, fingers, or toes going numb. It can be harmful if you also have a respiratory condition.



Do you ever wish you could have direct access to a Neurologist for your CMT questions? Now you can! HNF is proud to present our new web page featuring real questions from CMT patients across many topics. Submit your questions directly from our site to Directors of the Hereditary Neuropathy Foundation Centers of Excellence at St. Louis University, St. Louis, MO, and at Hackensack University Medical Center, Hackensack, NJ, Dr. Florian Thomas and Dr. Jafar Kafaie today!

Q: My calf muscles have wasted away, affecting my balance and walking. Can these muscles ever be restored?

A: Dr. Florian Thomas:

Thank you for sharing that question. In CMT the calf muscles waste away because the nerve fibers to the muscle are damaged. In order to avoid this the disease process in the nerve fibers must be halted or reversed. That is the goal of numerous CMT drug trials in various stages across the globe. Some of these experimental drugs target only specific genes that are mutated in CMT, while others may benefit patients with different CMT subtypes. While we have had encouraging news from some of them, none are yet close to FDA approval.

HAVE A QUESTION?

www.hnf-cure.org/ask-the-expert



HNF's New Center of Excellence: Austin Neuromuscular Center

DR. YESSAR HUSSAIN

Yessar Hussain is board-certified in neuromuscular medicine, neurology, clinical neuromuscular pathology and electrodiagnostic medicine. He completed his fellowship in neuromuscular medicine and electromyography at Washington University School of Medicine/Barnes-Jewish Hospital in St. Louis after his neurology residency at State University of New York's University Hospital in Syracuse. He received his M.D. from the University of Baghdad, College of Medicine in Baghdad, Iraq.



Dr. Yessar Hussain

Dr. Hussain is an assistant professor in both the neurology and physical medicine and rehabilitation residency programs at Dell Medical School. He was the neurology clerkship director at the Neurology Department at University of Texas Medical Branch, Austin from 2013 to 2015 and assistant professor at UT Southwestern from 2012 to 2014.

In addition, Dr. Hussain is director of Austin Neuromuscular Center, which provides comprehensive neuromuscular services and educational and teaching opportunities for medical residents and students.

Q: WHY IS CMT YOUR PASSION?

Most CMT patients I see are very active and motivated. These patients do their best to prevent the disease from impacting their daily living. I always want to help in any way, to manage their symptoms, not just diagnose, but I feel my help is limited and we need more research and treatment modalities.

Q: TELL US WHAT PATIENTS WILL EXPERIENCE WHEN THEY COME TO THE AUSTIN NEUROMUSCULAR CENTER?

At our center, we try to achieve a comprehensive approach to neuromuscular disorders to reach an accurate diagnosis. In addition, we are committed to research advancement and the best care possible.

Q: WHAT DO YOU LOVE MOST ABOUT YOUR PRACTICE?

Our friendly staff, commitment to research, and broad coverage of neuromuscular disorders.

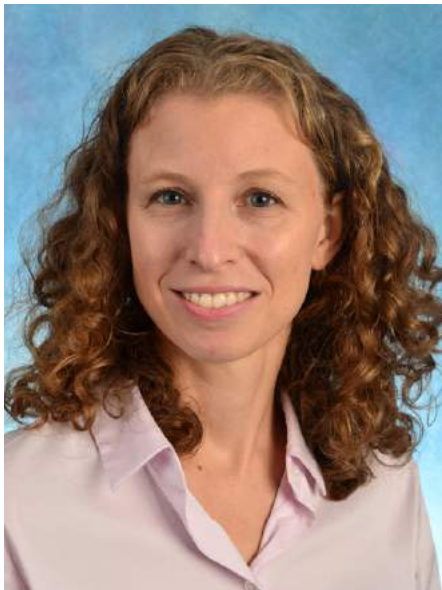
Q: HOW CAN PATIENTS MAKE AN APPOINTMENT AT AUSTIN NEUROMUSCULAR CENTER?

I recommend visiting our website austinneuromuscle.com

We try to accommodate every patient, even if they are out of network, or have no insurance.

HNF's New Center of Excellence: University of North Carolina

DR. REBECCA TRAUB



Dr. Rebecca Traub

Q: WHY IS CMT YOUR PASSION?

I have both personal and professional interests in CMT. I have a number of family members affected by CMT and have seen how the disease affects people in my personal life. I have also seen how resilient people with CMT can be in adapting to their disabilities.

Professionally, it is an exciting time to treat patients with CMT. The field of genetics has expanded rapidly in the past ten years and we continue to learn many new things about how hereditary neuropathies can present in diverse ways. Additionally, we are just beginning to see a breadth of new therapies developed for many genetic disorders, including a number of hereditary neuropathies. I am optimistic that there are a number of exciting new research studies and approved treatments on the near-horizon for patients with CMT.

physical therapist, occupational therapist, orthotist, and orthopedist if needed.

Additional consultations with other allied health providers or medical specialists can be arranged through the UNC system when needed. We discuss CMT research progress at our visits and what research trials may be applicable to any given patient.

Q: WHAT DO YOU LOVE MOST ABOUT YOUR PRACTICE?

I love that I get to see a broad range of patients with neuromuscular disorders (many with CMT), coming from diverse backgrounds. I get to treat patients living in the research triangle surrounding Chapel Hill, as well as the broader state of North Carolina and the greater region. I get to work with amazing colleagues in Neurology and other medical and surgical specialties, supporting patients with excellent clinical care and advancing medical research at the institution.

Q: TELL US ABOUT YOURSELF?

I completed my training in Neurology and Neuromuscular Medicine at Columbia University, where I became specifically interested in treating patients with peripheral neuropathies. After practicing as faculty at Columbia for a number of years, I moved to the University of North Carolina four years ago. I have enjoyed developing the peripheral neuropathy program at UNC and focusing on building a program dedicated to serving patients with hereditary neuropathies.

Q: TELL US WHAT PATIENTS WILL EXPERIENCE WHEN THEY COME TO THE UNC CENTER

Patients evaluated at the UNC CMT center may be seen for consultations first trying to establish whether they have an inherited neuropathy or to get genetic testing to establish the CMT type. Once a patient has been established in the center, they will be seen in the interdisciplinary clinic, seeing the physician, nurse,

Q: HOW CAN PATIENTS MAKE AN APPOINTMENT AT THE UNC CENTER?

Patients wanting to be seen at the UNC CMT center should ask their primary care or other treating physician to send a referral either by fax, email or electronic portal. Full instructions are on the Department of Neurology website at: www.med.unc.edu/neurology/new-patient-referrals-1/adult-referrals



HNF's CMT Centers of Excellence

The national network of HNF-designated Centers of Excellence (COE) provides patients with resources to find hubs of expertise in caring for and treating CMT, as well as locations where CMT research is being conducted. Our primary goal is to ensure care results in positive outcomes for each individual patient's clinical experience. We are honored to partner with these premier Centers and their leading experts to improve the future for people with inherited neuropathies.

ARKANSAS

Arkansas Children's*

Little Rock, AR 72202-3591

Contact: Dr. Aravindhan Veerapandiyan

Primary Care Appointments: 501-213-1883

Specialty Care Appointments: 501-819-3520
Hospital *Pediatric Center of Excellence

CALIFORNIA

Cedars-Sinai Medical Center

Los Angeles, CA

Contact: Tara Jones tara.jones@cshs.org

CMT Clinic line 310-423-4268

Stanford Neuroscience Health Center Neuromuscular Clinic

Palo Alto, CA

Contact: Jennifer Fisher jnfisher@stanford.edu

CONNECTICUT

Hospital for Special Care

New Britain, CT

Contact: Sharon McDermott 860-612-6305

FLORIDA

AdventHealth Neurology at Winter Park

1573 W Fairbanks, Ste 210

Winter Park, FL 32789

Contact: Nivedita Jerath MD, MS 407-303-6729

Orl.neuromuscular.medicine@adventhealth.com

University of Florida Health

Gainesville, FL

Contact: Tracie Kurtz, RN, CCRP 352-273-8517

tlkurtz@ufl.edu

University of Miami

Miami, FL

Contact: Meri Jaime (for appointments)

305-243-7400 MJaime@med.miami.edu

ILLINOIS

Ann and Robert H. Lurie Children's Hospital of Chicago*

225 East Chicago Avenue

Chicago, IL 60611

Contact: 312-227-4471

KANSAS

University of Kansas Medical Center

Kansas City, KS

Contact: Nicole Jenci 913-945-9934

njenci@kumc.edu

MASSACHUSETTS

Brigham and Women's Hospital

Boston, MA

Contact: Kristen Roe 617-525-6763

kroe@partners.org

MICHIGAN

University Of Michigan

Ann Arbor MI

Contact: Keianna Banbury 734-763-2554

kbanbury@med.umich.edu

MINNESOTA

University of Minnesota Health

Maple Grove, MN

For Research Studies: 612-624-7745

CNRU@umn.edu

For Clinic Appointments: 763-898-1080

MISSOURI

St. Louis University Medical Center

St. Louis, MO

Contact: Mrs. Molly Labrier 314-977-6177

molly.labrier@health.slu.edu

MU Health Care

Columbia, MO

Contact: Dr. Raghav Govindarajan 573-882-1515

govindarajanr@health.missouri.edu

NEW JERSEY

Hackensack University Medical Center

Hackensack, NJ

Contact: Florian Thomas, MD, PhD 551-996-8100

Annerys.Santos@HackensackMeridian.org

Atlantic Health System*

Morristown, NJ

Contact: Dr. Jahannaz Dastgir 973-971-5700

jahannaz.dastgir@atlantichealth.org

NEW YORK

Columbia University

New York, NY

Contact: For clinical appointments

Allan Paras 212-305-0405

For research studies 212-305-6035

ap3476@cumc.columbia.edu

NORTH CAROLINA

Dr. Rebecca Traub

University of North Carolina

194 Finley Golf Course Road, Suite 200

Chapel Hill, NC 27517

Contact: For clinical appointments

984-974-4401 Referral Fax: 984-974-2285

TEXAS

Austin Neuromuscular Center

3901 Medical Parkway, Ste. 300

Austin, TX 78756

Contact: Yessar Hussain, MD 512-920-0140

Website: austinneuromuscle.com/contact

WASHINGTON

St. Luke's Rehabilitation Institute

Spokane, WA

Contact: Ann Cooper 509-939-8079

coopera@st-lukes.org

* Pediatric Center of Excellence

Attn: Parents of
TEENS^{with} CMT



We want to expand
programs for teens
living with CMT...
Please take our
6-MINUTE SURVEY
to help us learn about
your child's needs



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LINK: surveymonkey.com/r/DJF8PZX



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New York, NY 10016
hnf-cure.org

HNF Event Highlights

Get Involved and Join us at an Upcoming HNF Event



Million Dollar Bike Ride Goes Virtual

Despite the current situation with COVID-19, HNF was still able to participate in the virtual Million Dollar Bike Ride (MDBR) fundraising event. We had riders from across the United States with participants in Seattle, Chicago, Pennsylvania and New York!

Riders were able to partake on their own with a street ride or on a stationary bike that was hosted by the MDBR Orphan Disease Center @UPenn.

For the closing ceremony, HNF's video with Founder Allison Moore was featured.

Thank you to ALL the riders that participated. **There is still time to donate. We are close to our goal – can you help us reach it?!**

View the amazing video about Allison's motivation to participate in this ride and make a donation for important CMT research.

Watch video and donate:
hnf-cure.org/million-dollar-bike-ride



Inaugural Jaxson's Crusaders Clay Shoot

On Saturday June 20, 2020, the Flynt Family and their close friend Heather Guerrero held the inaugural Jaxson's Crusaders Clay Shoot to raise money for gene therapy research. The Flynt's son, Jaxson, was diagnosed with Leigh syndrome C12orf65 five years ago and they have been raising money for research ever since. The event was family friendly and included a bounce house, face painting and kids' games. The clay shoot had over 130 shooters and around 175 total participants raising \$29,000. They are looking forward to their next charity clay shoot in Fort Worth on Saturday October 31, 2020.

JaxClayShoot.givesmart.com

To donate to Jaxson's Crusaders:
www.hnf-cure.org/jaxsons-cure

